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ABSTRACT

This study explains the characteristics and treatment of individuals with Rett Syndrome and presents two case studies that investigated the use of interventions in reducing stereotypical hand movements (SHM). The case studies involve two girls (ages 5 and 7) with Rett Syndrome who were enrolled in a special education school. Information was gathered on using different types of intervention to reduce SHM, including elastic bands and vibrators. The study found an inconsistency of effect of elastic bands and vibrators on the girls. Other findings include: (1) swinging in the swing had a positive effect on reducing SHM; (2) one of the girls preferred a tactile message to the hand, and rejected deep pressure through the joints; (3) the availability of objects and their distance from the girls (especially to the less ambulatory girl) had a great effect on the level of engagement with objects and response to external stimuli; and (4) the most effective position was found to be prone with objects 50 cm diagonally from the girls. Information sheets that could be used as overheads or handouts are attached. (CR)

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Reduction of Stereotypical Hand Movements in Girls with Rett Syndrome: Two Case Studies

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ED 404 792

Literature Review

Rett Syndrome was first reported in 1966 by Dr. Adrias Rett, However only in 1983 when it was redefined by Dr. Hagberg it received it's name and recognized as a distinct Syndrome (Hagberg, 1993). The Syndrome is characterized By :

* Females
* Slowness/Loss of Motor Ability
* Loss of Hand Use, Appearance of Stereotypical Movements
* Loss of acquired Speech
* Loss of Interest In The Environment
* Autistic Like Behavior
* Apraxia
* Difficulty In Mobility
* Breathing Difficulties
* Irregular EEG
* Seizures, Changes in Peripheral Blood Flow
* Change in Muscle Tone, Spasticity and Rigidity
* Deformation of The Spine, Limbs.

Despite extensive research in the last 10 years, no genetic or chemical explanations have been discovered that will enable early identification. Also no medication or effective treatment has been proven to have long term positive effect.

The most dominant aspect of treatment remains in the hands of paramedical professionals. One of the most studied aspects of treatment is the attempt to decrease stereotypical hand movements which are characterized in wringing, mouthing and washing. Some of the studies report increased attention span as a result of reducing the SHM. Lindberg (1988) reported that use of hand splints to reduce hand movements caused the appearance of movements in other body parts or an increase in the SHM once the splints were removed The literature reports several intervention strategies:

I. Bilateral hand movement restriction:

*Hard splints to the joints found to be effective in increasing daily activities (Kubas, 1992; Sharp, 1992)
*Soft Splints to the joints.
*Tak Bak Voice machine which reduced placing the hand in the mouth.
*Towel wrapping on the hand to avoid mouthing
*Water floats on the arms
*Hand splints to avoid abduction of the thumb found effective.

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II. Unilateral hand movement restriction - of non preferred hand:
*soft splints
*Side sitting and weight bearing on the side of the non preferred hand.
*Placing active hand under the table while feeding or table activities.
*Weights on non dominant hand base.
*Hand restraint by therapist.

III. Gross motor activities which require hand use
*walking up steps
*riding a horse
*swinging on a swing
*pushing a baby carriage
*finger feeding
*jumping on a trampoline

Other intervention include use of dominant hand, sensory awareness, distracting stimuli in the form of holding objects, dancing, music. Also reported effective are overcorrection activities.[2]

Rational for present study

After extensive work with the girls and the observation that the majority of their awake state is engaged in SHM (Lindberg, 1988), it seems that the need for these movements comes from a proprioceptive/vibratory deprivation. Thus providing them with an alternative might decrease that need and relieve them of these movements, so that as a direct result they will be free to engage in purposeful activity. Lindberg (1988) Hanks, (1986) reported the use of vibrating pillows. Also mentioned is brushing of the palms of the hands, the use of a vibrator so that the hand grasps the vibrator with the therapist closing off hard to the hand.

The Study

Subjects

Two girls (ages 5 and 7 years old). Both in the III stage of the condition (stable condition, a plateau with all symptoms). These girls are enrolled in a special education school at Beit Issie Shapiro, an organization providing therapeutic, educational, recreational and community services to the developmentally disabled and their families.

Eye contact with objects increased with EB in comparison to baseline (EB 18.6%; baseline 10.8%). Eye contact (16%) with vibrators was in the middle in terms of effect. Eye contact with people was highest with no intervention (4.3%) and lowest with vibrators. Functional Hand Use was best in the baseline condition and was lowest with the intervention (baseline 16.7%; vibrators 5%; EB being in the middle 6.7%). Clearly there is no one preferred condition or most effective condition based on the intervention. Also it seems that this girl engaged the least with eye contact when these aspects are measured.

Table 3 Shows best results in terms of reduced Stereotypical Hand Movements in the EB condition (27.3%) and vibrators being the worst (29.7%). Eye contact with Objects showed best results with EB (16.9%) and baseline being the lowest (12.8%), the vibrators had some positive effects (15.5%). Eye Contact with People was best with EB (6.3%) and worst with vibrators (1.5%). Functional Hand Use was best with EB (10.6%) and worst in baseline (9.4%). For child No.2 the EB was clearly the best condition in terms of items measured.

Table 2 Analysis by activity when comparing the condition of with or without vibrators shows that feeding with vibrators reduced SHM (36% from 46% in other activities). Feeding was the worst activity in terms of SHM (without vibrators). Individual activity with vibrators had the best effect on Eye contact with objects (22.5%). Eye Contact with people was best in individual activity(10.8%). Functional hand use was best in Spontaneous activities without vibrators.

Table no.4 The comparison is between spontaneous vs. feeding activities only. Feeding activity with vibrators had best effect on SHM (18%). Eye contact was best with vibrators in spontaneous activity (14.8%). Eye contact with people was best without vibrators in spontaneous activity (3.4%). Best functional hand use was in the feeding activity with vibrators (23.8%).

Discussion

Results clearly show the inconsistency of effect between the girls and most importantly within each girl. Consistent with the literature the individuality of each girl is emphasized by these data and reflects perhaps the lack of commonality in characteristics of the girls despite the fact that they share a similar diagnosis. From a clinical perspective this study had a great effect (more than from

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Data Collection

Video recording under three different conditions: 1. No intervention (baseline): 2. Pre-intervention (elastic bands, EB), to assess effect; 3. Intervention (vibrators wrapped by elastic bands). These conditions were applied in three different settings (spontaneous; individual therapy; feeding).

Vibrator Description

Small vibrators which are activated by small batteries which operate by movements or by voice for 10 seconds and then stop unless reactivated.

Analyses:

A scale consisting of 6 items was developed based on the literature and clinical observation: 1. Stereotyping hand movements: 2. Functional hand movements (including weight bearing of upper limbs, scratching irregular body parts, hand reaching to objects, object manipulation, touching other as communicative intent); 3. Eye contact (including through mirror). The criteria for this item was joint eye contact. 4. Eye contact with objects (including mirror). 5. Attention to external auditory and tactile stimuli. It is interesting to note that the girls nose pick with the index finger that require accuracy and control which is paradoxical. 6. Smile, temperament, laughter/restlessness, cry screams. Items 5 & 6 were deleted due to poor reliability measures

Coders

3 coders were trained to analyze the tapes by the items specified. After an interrater reliability coefficient of .90 was reached the tapes were analyzed. Of the tapes 10% were analyzed by the three coders to assure no coder drift.

Results

As mentioned due to the significant difference between the girls baseline condition this should be considered as a two case study rather than a comparative study.
Table 1 shows a general effect of the intervention. The effect began in the EB condition and the vibrator intervention. Stereotypical movements increased with EB in comparison to baseline (EB 79.8%; baseline 72.5%). The lowest incidence of SHM were with the vibrator (43.5%).

a research perspective). The Therapist working with the girls discovered how critical the use of video in treatment is in terms of developing a more objective eye and a more analyzing observation of his /her work and the subject's response, a condition that is impossible in a treatment setting especially in a multidisciplinary classroom. As a indirect result of the study he discovered 1) that the swinging in the swing had a great positive effect on reducing SHM movements. 2) One of the girls prefers a tactile message to the hand, and rejects deep pressure through the joints. 3) It was found that the girls attempted more eye contact particularly with the paraprofessionals in the classroom and also with other children but received no response to their attempts. 4) The availability of objects, their distance from the girls especially to the less ambulatory girl had a great effect on the level of her engagement with objects and her response to external stimuli. 5) Motor planning has been found most problematic and .6) The girls have a very high pain tolerance, when other children hit or stepped on them they did not respond. 7) the most effective position was found to be prone with objects 50 cm diagonally from the girls in terms of less SHM.

Limitations

These data should be accepted with great caution due to the simple analysis conducted and the limitations of a case study as well as lack of many more independent variables. Despite the interrater reliability there was great difficulty in distinguishing between functional and stereotypical hand use, intentional eye contact or incidental eye contact.
This study served as a pilot and is just one in a number of studies conducted at B.I.S. which emphasize field studies headed by clinicians working with the children. Presently we are in the midst of a study examining the effects of joint treatment of physical therapy and music therapy on 4 girls with Rett syndrome.

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DATA COLLECTION

N=2. AGES 5 AND 7 YEARS OLD.

VIDEO RECORDING

CONDITIONS

1. BASELINE - NO INTERVENTION.

2. PRE-INTERVENTION (ELASTIC BANDS (EB).

3. INTERVENTION (VIBRATORS WRAPPED BY EB).

SETTING

1. SPONTANEOUS

2. INDIVIDUAL PHYSICAL THERAPY

3. FEEDING

VIDEO ANALYSIS SCALE

1. STEREOTYPICAL HAND MOVEMENTS.

2. FUNCTIONAL HAND MOVEMENTS.

3. EYE CONTACT WITH PEOPLE.

4. EYE CONTACT WITH OBJECTS.

5. ATTENTION TO EXTERNAL STIMULI (Not included in analysis).

6. TEMPERAMENT (Not included in analysis)..

CHARACTERISTICS OF RETT SYNDROME

* FEMALES
* SLOWNESS/LOSS OF MOTOR ABILITY
* LOSS OF HAND USE. APPEARANCE OF STEREOTYPICAL MOVEMENTS
* LOSS OF ACQUIRED SPEECH
* LOSS OF INTEREST IN THE ENVIRONMENT
* AUTISTIC LIKE BEHAVIOR
* APRAXIA
* DIFFICULTY IN MOBILITY
* BREATHING DIFFICULTIES
* IRREGULAR EEG
* SEIZURES,
* CHANGES IN PERIPHERAL BLOOD FLOW
* CHANGE IN MUSCLE TONE. SPASTICITY AND RIGIDITY
* DEFORMATION OF THE SPINE. LIMBS.

TABLE 1

CHILD No 1

BY INTERVENTION**

Item Measured / Intervention	Stereotypic Movements	Eye Contact with Objects	Eye Contact with People	Functional Hand Use
Baseline	72.5	10.8	4.3*	16.7*
Elastic Bands	79.8	18.6*	0.1	6.6
Vibrators	43.5*	16	0.58	5

* **Most desirable**

** **By percentage**

TABLE 2

CHILD No 1

BY ACTIVITY**

Activity	Item Measured	Stereotypic Movements	Eye Contact with Objects	Eye Contact with People	Functional Hand Use
Spontaneous	With vib	46	20	0.2	6
	Without vib	50	13.9	1.1	18.8*
Individual	With vib	46	22.5*	2.3	1.1
	Without vib	-	3.5	10.8*	0.7
Feeding	With vib	36*	6.2	0	0.9
	Without vib	88	7.7	1.95	0.065

* **Most desirable**

** **By percentage**

TABLE 3

CHILD No 2

BY INTERVENTION**

Item Measured / Intervention	Stereotypic Movements	Eye Contact with Objects	Eye Contact with People	Functional Hand Use
Baseline	29.7	12.8	4.1	9.4
Elastic Bands	27.3*	16.9*	6.3*	10.6*
Vibrators	47.5	15.5	1.5	10.3

* **Most desirable**

** **By percentage**

TABLE 4

CHILD No 2

BY ACTIVITY**

Activity	Item Measured	Stereotypic Movements	Eye Contact with Objects	Eye Contact with People	Functional Hand Use
Spontaneous	With vib	52.5	14.8*	0.5	8.9
	Without vib	46.5	4.4	3.4*	8
Feeding	With vib	18*	11.8	11.8	23.8*
	Without vib	36	13.6	13.6	0.7

* **Most desirable**
** **By percentage**